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ABSTRACT

This report presents findings of a Minnesota study group which reviewed the costs and structures under which developmental disabilities services are provided. The group conducted a series of town meetings throughout the state and concluded with a toll-free call-in day. Six themes emerged from the meetings: (1) "We have a lot to be proud of and much remains to be done" (e.g., more support to families and improved coordination of services for children); (2) individualization (e.g., individuals and families want more decision making powers, and case managers are overworked); (3) staffing (poor pay and high turnover); (4) leadership and bureaucracy (there is too much red tape and too little attention to quality; (5) inequity of resources and inconsistencies in the system (too much inconsistency among counties and between rural and urban areas); and (6) community programs and support (waiting lists are long and there is a need for respite care services). Specific study group recommendations address: individual and family support, increased funding for community programs, renegotiation of waivers, array of available services, coordination, case management, alternative approaches to quality, quality assurance functions, planning data, and guardianship. (DB)

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THE GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

NOVEMBER, 1992

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MINNESOTANS

SPEAK Out!

A SUMMARY OF TOWN MEETINGS HELD THROUGHOUT MINNESOTA ON DEVELOPMENTAL DISABILITIES ISSUES

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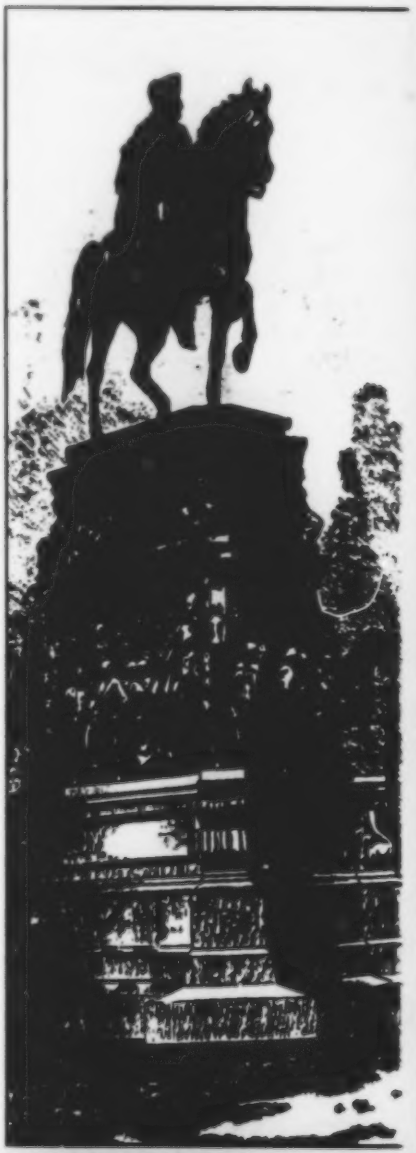

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INTRODUCTION

On January 27, 1992,
Deputy Commissioner, George Steiner, DHS
appointed a study group to
"review the current structure under which
developmental disabilities services are provided
and to review costs."

This group met from February
to August, 1992.

At the first meeting,
the study group decided to seek input
from Minnesotans through a series
of town meetings.

This report summarizes the themes
discussed at these town meetings
and a toll-free, call-in day.
The report concludes with recommendations
from the study group.

Town Meeting Highlights:

Here is the good news:
Programs such as personal care assistance (PCA), semi-independent living services (SILS), family support, early intervention, waivers, supported employment, and others were described as:

Miracles...Superior...Effective...Visionary!

These are good ideas that need to get back on track.

- The waiver has been lost to a "lottery for slots, conversions, diversions, backfilling, and being held hostage."
- Residential gridlock occurs when movement is based on death or placement from a regional treatment center.
- Focus on the customer by answering phone calls and letters. Use common sense and respect. Demonstrate cooperation. Provide correct information.
- Licensing must assess quality of life not foster paperwork or regulation and negative approaches.
- Case management doesn't work if caseloads are too high. Training does not occur, turnover is high, and it ends up being all paper pushing.

These systemic issues are broader than developmental disabilities.

- Personnel issues such as low pay, high turnover, and poor training undercut quality and stability in community settings.
- Waiting lists do exist.
- The future of regional treatment centers continue to affect all policy decisions.
- Individualization is lost.

Certain targeted issues require cooperation.

- **We need a retirement policy for citizens who are aging.**
- **We need respite and caregiver support.**
- **We need more flexibility in decertifying a few beds in an ICF-MR.**
- **We need to pay attention to the special needs of individuals with developmental disabilities who may also be deaf or who have epilepsy.**

THEME ONE:

We have a lot to be proud of and much remains to be done!

At town meetings and in letters and phone calls, people spoke of the advances that we have made in Minnesota over the last decade. They spoke of a new vision of how life should be for people with developmental disabilities.

And, they spoke of the fact that the vision has yet to be realized for many, if not most, Minnesotans with developmental disabilities. They described how people with developmental disabilities often have to rely on services which do not meet their needs but are the only options open. They despaired over the fact that our gains are at risk, what we have built is being eroded.

We Have Done Much

In two communities, for example, we heard that the challenge of the last decade has been met.

In spite of all this and other problems, we have a good delivery system that should be the pride of our nation. We do a better job of providing community services and supported employment training to persons with developmental disabilities than anywhere else on the planet and that is statistically proven. We have emptied our regional treatment centers. and we have transformed our services to meet the needs. We have met the challenge well.

You can bitch and complain, but progress has been made. ICF-MR and RTC use is down. SILS, Waiver, SLAs, and Family Support have increased. In St. Louis County, 140 people live in waivered services which is great. Everyone has had to change. Let's work together because there will never be enough money. Keep the focus on people's lives. We are fortunate to be in Minnesota and the United States.

Support to families

Our family has received family support since the late 1970s. Thank you but please expand to other families.

Home-based services are essential. TEFRA works. I'm tired of advocating for a program that's critical and cost-effective. DHS refuses to say how much money is saved and how much money is collected in fees.

The most important and essential service our family receives is home health care. It is the best, we couldn't live without it. It keeps us sane. We can be employed. We have opportunities. However, health aides are poorly trained. Turnover is staggering.

The Children's Home Care Option and Waiver are miracles. Children with disabilities are now eligible for Medicaid because parents' income is deemed. As a result, no child from Olmsted County is placed out of the home. We don't even think about placement of children. The pressure is off.

Early childhood and public education

The early intervention process works to help coordinate providers (education, human services, and health). At kindergarten or age 7, the coordination ends. It should continue.

My son is in public school. He has full inclusion and not mainstreaming. I want this to continue. No group home. I want him to have a life.

In community after community, people pointed to the contribution specific programs have made. They identified advances in early intervention, public education, supported employment, the impact of waivers, and the positive impact of community programs in general. And often in the same statement, they identified a challenge which we have yet to meet.

"There are miracles due to the activities of government and advocates. A Newsweek article describes the first day of school for a young boy with cerebral palsy. He was riding the regular bus with neighborhood kids to go to a neighborhood school. It may be a routine beginning for most children, but it was a miracle for this family. Government spending does make a difference.

My two children have Fragile X. Early childhood staff were plentiful and caring. But what a difference between early childhood and education!

Our special ed coop funded a transition facilitator with the county. This person writes the ISPs, coordinates assessments, and conducts a Personal Futures Planning process. It is a positive program.

Community programs

Since 1985, the waiver has significantly affected the lives of people with disabilities. The problem is we have a lottery for the slots available.

The waiver is a superior program; but with no rate increase, it is an injustice. We need inflation increases for every community program. We have people on the waiver who would cost $300 per day in a regional treatment center (RTC), but now we're spending $165 per day on the waiver with no increase.

The community programs have given my daughter more skills than we ever thought possible."

The vision for the past 30 years has allowed a blossoming of the community. But as important and as valued this vision is, we are strangled because of a lack of money.

Minnesota has nice laws on the books, but there's no enforcement. I'm left wondering why things aren't happening for my son, why I'm frustrated and angry.

Supported employment

People are out working who have never worked before. We have 20 new work sites, and the people are gainfully employed.

Supported employment is a cost-effective, viable option. Employment restores dignity and community participation. However, no state funds are available for supported employment. We must shift the funds.

Supported employment has given my son self-confidence, assertiveness, and dignity. Supported employment has done more for him than 25 years with his family.

We have had a success that I'd like to share. The RTC discharged a woman who was told, "You'll never make it." "She has no concept of work or money, she will ingest the money." Five months later, she earned $100 a month. She has a good idea about money. She does need one-to-one assistance, and her Special Needs funding is being cut. How can we target to greatest need?

And Much Remains to be Done
Fears about losing the RTC as an option

In town meetings, letters and phone calls, people identified the challenge of closing the Regional Treatment Centers. For some families, the RTCs represented the only choice at the time and is still so today. To them, the RTC represents the only option that ensures safety and security. For others, the RTCs remain the only choice, but they are seen as neither safe nor secure. For many, the challenge is to develop supports in the community for all.

The following statements capture the dilemmas shared by many.

One letter writer sent a copy of a letter sent eight years ago that had identical concerns. Her daughter was placed 22 years ago in an RTC. "Closure would be a disaster... Community facilities are poorer quality... Don't sacrifice my daughter and all the benefits... As a parent, I am capable to be the judge of what is best. The staff provide expertise and loving care. How will monitoring [in the community] occur?"

Another letter made the following points about RTCs: People with the most severe disabilities are pawns and numbers in a political game... They need a large facility with professional, experienced, dedicated staff which is not possible in a group home... Don't move more people out of regional treatment centers until the community is ready for them... Those who want to close the programs have no one at the regional treatment centers or have never visited... Instead of moving professionals from the regional treatment centers to the community, it makes more sense to move people with mental retardation back to the regional treatment centers.

Lack of options to the RTC

We need a regional treatment center to help our son. We can't do it alone. We had no choice. [The RTC] provided everyone with a home. In 1962, our daughter was severely brain damaged. She is 38 years old and has seizures. [Our county] may have wonderful programs, but [our daughter] doesn't fit in. [The RTC] saved our lives. They were wonderful. They protected her with no judgments made against her. They discovered her artistic talents. They have wonderful personnel.

We're not horrified by the RTC. It is God's gift. It is dramatically different from 30 years ago. Open other options before you close [this RTC]. We'd be happy to have our daughter in the community, but no one will take her.

I have spent time at every RTC. The paradox is that I wouldn't want to live there, but the staff have impressed me. They are caring, competent, and professional. Lots of bad incidents have hit the press.

Why isn't there follow-up from the RTC to the community? Too many people are coming back to the RTC "messed up." Residents are sent to strange places with strange people; it's not their choice; they lose weight.

Fears about the RTCs

I'm very frightened about fire safety at the RTC. There are lots of residents and only one staff. I've been everywhere to express my concern including the Governor's Office, but no one does anything. There is no backup system. Two people are necessary to move my son. If there's a fire, he may not escape safely.

RTC staff are working double shifts. That's dangerous.

My son needs 1:1 assistance. In case of fire at night, my son will not get out.

The Regional Treatment Center is Grand Central Station. There are no stable relationships.

We observed the RTC. There was no interaction between the staff and residents. One of the residents went into the community once every other month. Since he left the RTC, he has been out once or twice a week.

Obstacles to change

Money doesn't follow people from the RTCs.

We need to be more aggressive in closure of RTCs. People with disabilities should live in the community and not the RTCs. We need to do what's good for people. RTCs aren't good for people. Given our financial picture, we are spending too much money on RTCs.

The new vision

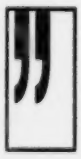
My vision is my son will be in our home, not in their RTC; included in our school, not their special education program; included in our day care, not their special day care.

Others expressed concerns about the need for pediatric nursing homes, and access to nursing homes in general.

One parent called whose daughter is four years old and mentally disabled. The daughter lives in a nursing home. They have a special unit in pediatric care for individuals with special needs. The consultant with the Department of Human Services (DHS) has taken the view that children with developmental disabilities should not be in nursing homes. When the consultant toured the facilities, she described the problem as their not having active treatment. The parent stated that ICFs-MR had been toured, but do not offer or provide the needed services. It seems to be DHS's policy that there be no future admissions and the good program that now exists may be terminated.

In total, there were at least twelve calls supporting the opening of a pediatric nursing home.

Another family member described her difficulties in getting her brother into a nursing home. She has a brother who lived in a group home for 20 years. When his health deteriorated, the family worked with the social worker and the director of the group home. They found a nursing home which had an opening and was willing to take the brother. BUT...



"The state denied him placement in the nursing home because of the OBRA law. DHS did not feel that his medical needs were such that he be placed in a nursing home, plus he needed continued active treatment, as part of the law. To add to this dilemma, the family searched high and low for another facility, and there was none. For seven months the search continued. In the meantime, my brother was put in the hospital for a dislocated kneecap and at that point, of course, we absolutely had to find another place to live that was fully accessible.

For seven months we have had to fret and worry when he could have been in the nursing home. Just last Friday, we were told that the facility in Willmar would now be permanent. We went through a board of appeals meeting to overturn the decision of denial of admission to the nursing home. We were denied. I feel that if my brother was not mentally handicapped, he would have been, without a doubt, a candidate for a nursing home. The OBRA law is discriminating against people with mental handicaps... There must be something wrong with the law, when the family and the people who have taken care of my brother for over 24 years make a decision that can be denied by individuals in a state department who have never seen my brother.

I also wanted to be my brother's legal guardian because he has always been a ward of the state. DHS denied my taking over as guardian. They said that they were doing this in the best interest of my brother and this was for his own safety. I said this was for his own safety from his family? This was an insult. Legal guardianship is going to be taken care of by our social worker."

Many described significant achievements in the community over the last few decades, and noted that those opportunities are not available to them.

In the Metro/St. Paul meeting, a parent said that "community programs have given my daughter more skills than we never thought possible." And another parent described her struggle to share the same kind of experience.

In community after community, families celebrated the impact of early intervention and early childhood programs, then described the barriers to the inclusion of their sons and daughters in the schools and classrooms of the public education system.

In 1988, we wanted to place our daughter on a waiting list for the waiver. No list existed. In 1990, the case manager had a caseload of 100. On April 16, 1991, a waiver is available. On August 20, 1992, still no placement. Constant delays. The group home is causing regression. She has been inappropriately placed for two years.

Elementary teachers act like, "Why are you here?" To get our son in kindergarten, we had to go to five different people and Legal Advocacy.

Special education teachers don't even bluff. They say they're too busy and overwhelmed. Teachers are doing two to three person's work.

Transition occurs at age 17 1/2 years. That's too late.

The schools and adult services must come closer together. The curriculum should be changed.

Too many people leave high school and hit the wall. They're left doing nothing.

For many, continuity between school and adult services is a major issue.

One caller was the parent of a daughter with a developmental disability who has been in an adult program for two years. The parents looked for transitional programs following high school graduation, and did not feel there were sufficient choices. There was nothing available to teach their daughter the basic skills she needs to learn. Everything in adult programs is focused on job orientation, which they do not feel is appropriate for their daughter. Another problem is, unlike the school situation where the staff/student ratio was 1:1, the best ratio in the community is 1:4.

What good is that if it means a person spends three quarters of every hour waiting for services? You need to remember in planning programs to take into account the individual needs of each person. State guidelines are necessary, but should not be inflexible.

During public school years, emphasis is placed on self-help and social skills. My sister knew how to eat properly and display manners. Now that she lives in a group home, she doesn't have manners. According to the group home staff, she is an adult and can do what she wants. This lack of continuity may set her up for life-long exclusion. Adult providers don't seem to be getting proper information or training.

My recommendations are:

a) require at least one coordinator at all programs to be certified in special education.

b) pay staff salaries of adult services equivalent to school salaries.

c) state agencies must pull together a common philosophy for all providers.

d) encourage cross-training to foster a common philosophy.

e) funding must support families and clients.

One caller suggested priorities and an agenda for change:

- Too many people on waiting lists for all types of residential services, especially for persons now living with their families.
- Need to reduce waiting lists for family subsidies for adults, day services, and other types of supports.
- Need to develop a more aggressive crisis prevention strategy (behavioral crisis and medical crisis) for people in residential settings and in family home.
- Need to establish a more appropriate crisis intervention system.
- Need to continue to revise service delivery systems to increase focus on community inclusion.
- After addressing the waiting lists for people living with their families, we need to continue to work on moving people from large institutions to smaller homes.
- Need to establish a creative strategy to fund outcomes for all types of providers that are consistent with current state-of-the-art practices.
- Need to train staff on how to facilitate community inclusion.
- Need to address conflict of interest between guardianship and case management roles.
- Need a systematic retraining system for staff leaving RTCs or other institutions for employment in small community homes.
- Need to find ways to fund day services for people with challenging behavior who are expensive to serve without building new institutions.

"Quality supports in the community, for adults with developmental disabilities, were often described as a promise unmet.

Supported employment is one of the best, most productive parts of the service system, but it is most in jeopardy.

Minnesota is headed back to segregation. We can't continue day programs when we have cutbacks.

Programs are mandated, but no funds are provided.

We are institutionalizing community services. Improvements in people's lives come from flexibility.

Minnesota still leads the nation, but we are not advancing. We're hide-bound, and DHS is becoming muscle bound with flexing its regulatory muscles and parenting attitudes toward the provider. We must go ahead and not go behind."

When you speak to people with disabilities they say, "give us a job and a home of our own." It is a simple request, but extremely complicated to get. We must listen to the people.

There should be opportunities for people with developmental disabilities to directly control programs and provide services. The people have the right to determine the program and how to receive it.

Provide more opportunities for people to have Personal Futures Planning.

Programs need to be individually centered. Funds should follow the person.

The system fears individualization because then there's no need for a system.

DHS should encourage people with developmental disabilities to make choices for themselves.

The gap between reality and principle was pointed out time and time again.

Care isn't what people deserve. Residents have to deal with 20 new staff every couple of months. Nothing changes when rates are frozen.

We're pushing round pegs into square holes. Individualization doesn't exist. Policy and funding do not translate into individualization. We forget that this is a person.

We say individualized plan, but we don't fund it. We devalue life, and people deserve better.

In developing individual plans, there are too many details, we are too rigid; there is no flexibility.

THEME TWO:

Individualization

There have been tremendous changes in the ways we think about people with developmental disabilities and the best ways to support their efforts to participate in and contribute to the life of our communities. One of the hallmark changes in thinking has been the principles and concepts which call for a focus on the individual. Services and supports must be designed and delivered for the individual, and in ways that make sense for the individual with disabilities.

This concept is a cornerstone of federal and state laws in many areas, especially education, case management, and service planning. Being true to the concept requires systems and supports that listen to the individual and family, empower them to make and act on choices, and create opportunities so that people have choices upon which to act.

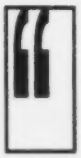
In each and every town meeting, the value and critical importance of focusing on the individual was stressed.

Parents, professionals, and people with disabilities identified three major categories of barriers:

State and federal funding patterns and rules result in a system that funds programs and types of services rather than individuals. Funds are linked to programs, not people. The amount of funding is determined more by the type of service than the needs of the person.

Case management, as a means of ensuring that individual needs are met and services are coordinated, has fallen far short of its promise.

Individuals with developmental disabilities and their families often have no choice. When people are able to only choose between one thing and no thing, there is no choice. Options are either non-existent or not available. Individual choice is severely and profoundly limited by "system gridlock" — no one can move because their way is blocked by others who cannot move.



Money Goes to Programs, Not People

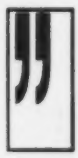
The system is driven by funding streams, not individual needs.

Where [the type of service] the person is located in the system determines money more than the person's needs. Let's address individual needs, not geographic location.

The amount of money you receive depends on where you live. Seven people may have identical needs, but the money differs based on where you live: RTC, SOCS, ICF-MR, waiver, SILS, foster care, and family in order of highest funding to lowest or no funding. It's inequitable, and there's no justice.

Our agency opened three ICFs and two waivered services. The individuals aren't different, but the per diems are very different.

One person can have two to three funding streams with his/her own eligibility criteria, regulations, and staff to monitor and manage the services.



People are held hostage because of the funding stream they are in.

My son is held hostage by the waiver rates. Our family wants a waiver, but there's no money. He's been a captive of the system for five years.

If you don't care about the family member, then move the person to the RTC and then move the person out on an enhanced waiver.

I want to move out, but I can't because the RTC must place someone in my facility. I like Luverne. I don't want to go back to Hennepin County. The system doesn't allow movement.

My son is 14 years old and lives in Windom. There are 26 beds in four units. My son can't move because his "open bed" can only be filled by a child from a regional treatment center. There are no children left in the regional treatment centers so he can't move. It's time for parents and advocates to start programs and have social services support them rather than the other way around.

People have a good idea of what is needed.

Make access to services easier. Link eligibility to pots of money. Money must follow the person.

Even though individual needs are similar, the funding doesn't match correspondingly. More money goes to certain programs.

We need to blend money to provide flexibility yet have safeguards to ensure funds aren't misused.

People with developmental disabilities and their families should control the funds.

Case Management

Case managers are over worked.

Case managers are overloaded. One case manager didn't complete routine paperwork because her caseload was 87 people. As a result, my family member didn't move.

Too much paperwork, too many monitoring requirements, and too time consuming. The ratios should be 25-30, but today, the ratios are 55-65+.

My son's case manager has a ratio of 222 cases to one case manager.

The caseloads are too huge. We never see the case manager. How can they write programs?

The ratios in [my] county need to be reduced by half.

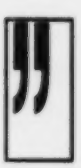
The service they provide is not always helpful.

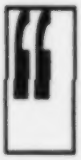
Case managers are unqualified and unlicensed social workers who have no background and no experience.

It's tougher to deal with the case managers (who are supposed to help you) than the children who have problems.

Case managers are improperly trained. At the ISP meeting, we decide on a program, but the case manager writes up a totally different plan.

Case management services billed under the waiver total $65 per hour. Those funds come out of the allocation for my daughter's care. Under an open market, someone could provide case management for half that amount. What happened to the parent-driven system?





As a case manager I am not going to move a resident receiving hundreds of dollars of services daily in a RTC to a placement that costs one-quarter of that amount. I will not set up a service that won't work. We need to decide the future of RTCs.

Some families have experience with an alternative.

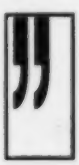
Parents as Case Managers training taught us that people have the right to be integrated in their own communities.

More training is necessary for Parents as Case Managers to assist counties.

Case managers do not know the people. We need clients to make their own decisions or assure enough case managers have low ratios.

Families who have taken training such as the Parents as Case Managers training are better advocates. We get our services when we know how to assert ourselves. Parents need to be treated with respect.

Parents as Case Managers [in our county] will not work because the county is unwilling and unable to give away power.



Individuals Have No Choices or Very Limited Ones

Funding and the rules (or their interpretation) hold people back.

We've been told to have visions and dreams. But our son has no choices. He faces slots and funding issues. He lives in a package deal—if he leaves, he moves with everyone else (six people in a group home). He has no choice of roommates, no technical college course work during the day, and no job in the community (only extended employment).

If federal funds are used for residential facilities, admission cannot be denied. Locally, a director of a nursing home has put a ban on people with disabilities. People with disabilities have the right to be there. Our daughter needs 24 hours of support. Support saves money in the end.

My daughter had a 65% productivity level. After one year in a sheltered workshop, her productivity level is 26%. Minnesota pays $600 a month so she can earn $6 a day. The provider told me she needs to be at 85% productivity level before she can be considered for supported employment. How can she be self-sufficient? (It was noted later in the meeting that not all programs have productivity standards for supported employment.)

Why can't we change the number of beds in a residential facility without closing it? DHS says we cannot decertify one or two beds, we have to decertify all the beds. People are changing because of aging or behavioral problems. Let's look at individual needs, not numbers.

Families are told about all their choices, but then we (case managers) have to say, "Don't pick it because you won't get it. Maybe in ten years."

In many areas of life, families want the supports that they think are best.

We don't want a Nursing Home for our son. That would be a full cycle of going back to an institution.

We need individualization. Why is everyone required to sit in a DAC or a nursing home or an ICF-MR?

The pendulum has swung from no in-home support to total in-home support. Thirteen years ago, our son received no supports until he left home, then he was eligible for everything.

It is abnormal to have strangers in your home 24 hours a day especially nurses. A family can have 25 different nurses in their home.

It's a "travesty and destructive" not to meet family needs in the home or out of the home. We need out-of-home respite.

My 26-year-old son with autism stays at home. There are no programs, no services, only the RTC. Minnesota believes in a small group home and day program for everyone, but this approach doesn't work for everyone. People with autism can be taxpayers if they learn skills.

Supported employment isn't for everyone. Don't forget physical, social, and recreational needs. There isn't enough money for supported employment, but we get citations anyway.

Individuals and families want control and the means to exercise control. They have ideas on how to get control.

All citizens with disabilities need to have choices of where they want to receive services and what to receive. Choice must rest with the consumer. We need more flexibility.

We need more flexibility and more individualization. We need vouchers so money can follow people.

We should look at the waivers for people who are elderly. It's not perfect, but money is based on needs. We can save money if people are allowed to pick and choose.

One choice means no option. We need to give people real choices and options.

Since 1973, the values have changed. We've moved from RTCs to community programs. Good business decisions mean shopping around. We spend a lot of money, but we aren't getting the best outcomes. Transfer money to the best services.

My wife and I can find better services than what the system offers us. Give us the money, and we'll find the staff. Families know best, but the system thinks the system knows best.

Put money and control in the hands of the people.

Families are cost-effective.

We must address the pay scales and turnover. If things don't go well for my son, it is usually because there's a training lag.

We are plagued by low pay and high turnover. Individuals with disabilities have to constantly get used to new staff and can't move ahead with such instability in direct care staff.

There is constant turnover of staff. My son is blind and has had 8 one-to-one staff in the last year.

I've worked with 5 providers and 36 personal care assistants. We have been sexually assaulted, physically abused, neglected, and experienced theft. Attendants have shown up high on crack cocaine. There are no regulations. My son will need surgery because an attendant caused a subdural hematoma. Surgery may result in brain damage. It was criminal sexual misconduct inflicted on a minor. Get it together. I'm tired of bureaucratic bull shit. Everyone suffers. When I complain, the county said, "I'm too difficult to please."

The staff are asking, "Whatever happened to the concept of home?" Residents want "time" with staff, but the staff are too busy providing active treatment.

Licensing staff tear apart direct care staff. We're required to be positive about people with disabilities, but licensing is negative about staff.

We had 36 health aides in 18 months. We've had nine new aides in the last two months. We've had four agencies in three years. The providers have poor communication and lack training.

THEME THREE:

Staffing

In every town meeting, there were repeated comments about the quality of staff in community programs, the impact that lower pay levels in the community have on staff turnover, and the need for training.

The specific issues center on pay scales, staff turnover, and staff training in community programs. High turnover means increased training and staffing costs. The fundamental issue, however, is the impact of all of these conditions on the lives and futures of people with developmental disabilities who are supported by staff.

The issues for people with developmental disabilities are quality of support, continuity of relationships with staff, and fundamental issues of safety.

The following town meeting excerpts identify fundamental causes of these situations and ideas on how to address them.

Staff are paid poorly and turnover is high.

In 1989, the Department of Employee Relations concluded that community employees earn 40% less than RTC employees, and the turnover rate is 60%.

The community staff earn 40 percent less than the public sector. Therefore, the staff take second and third jobs. There's no career path when you can't survive. The issue is wage equity.

The state wants high quality services but will not pay for it. Staff can earn as much money at McDonald's.

A person with a four-year degree earns $12,500 to $14,000 annually.

Community programs can't find good staff, and they can't pay. We interview applicants; and when they hear the pay, they say, "I can't afford to take the job."

A beginning staff person in a regional treatment center is earning $21,000 to $26,000 annually. I've worked 14 years in the community and still don't earn this range.

Staff turnover is deplorable. People deserve better care.

Our agency has 93 entry level positions and 81 of the 93 positions have new employees with less than one year experience. Turnover is directly related to wages. Turnover should be lower given the high unemployment rate on the Range.

The overriding mood of the town meetings was:

The system is not user friendly. Instead of enabling people to do things consistent with the vision, government has created a tangle of red tape and bureaucratic disablers. The vision of quality has been replaced by an obsession with paper compliance.

The focus should be, but is not, on quality. The red tape requires more resources and staff time for paper work, rather than people work.

The Department of Human Services is not exercising leadership. It is "acting like God...on a power trip... non-communicative... confused... and untruthful."

There is a crying need for team work and cooperation among and within government departments at all levels.

Generally, the system is complicated with a preoccupation for red tape instead of quality.

The system is very complicated. Some parts have good intent but no follow through. The entire system is not user friendly. We need to operate on common sense.

The Department of Human Services (DHS) says they are client-oriented, but they aren't.

The rules and regulations must be user friendly and based on the person's day-to-day activities. In my 16 years of experience, this is the worst I have ever seen.

Millions of dollars are spent on paperwork and process. Monitoring focuses on paper, not people. Paper is not equal to good lives.

THEME FOUR:

Leadership and Bureaucracy

Minnesota is seen by many as a leader in the field of developmental disabilities. One of the central themes of the town meetings was the perception across the state of that leadership. Leadership means many things, but includes having a vision of the future, drawing others to that vision, making it easier for people to do things consistent with the vision. It certainly means ensuring that people have resources and support to achieve the vision.

In every town meeting, consistent and serious issues were raised in terms of the leadership performance of the Department of Human Services, and other government bodies.

The concerns in these areas were not about tidiness in administrative systems, or an aversion to paper. They were about the current system (delivery of services, and eventually, the quality of life experienced by people with developmental disabilities).

Don't rewrite regulations. Get services aimed at individual needs. Get money to the people. Too much orientation to paperwork.

The rules and regulations that should enhance quality inhibit it.

The system isn't user friendly. The system has nothing to do with needs. Medicaid is degrading, humiliating, and exhausting. Children should be treated differently.

Specifically, there is little in the system geared to quality, and much that stands in the way of quality.

The rules and regulations that should enhance quality inhibit it.

Paperwork has exploded. In 1964, we had 60 clients and an administrative staff of 2.5 Full Time Equivalents (FTE). In 1992, we have 60 clients and 8.0 FTE administrative staff. The difference is paperwork and regulations (reviews, meetings, vulnerable adults, affirmative action, criminal background, medications, Rule 40, needs certification, licensure, CARF, etc).

I applied for Medicaid for my 13-year-old son. Eligibility is based on my son's income. His income is zero. We had to fill out an 18-page booklet that asked questions about family income which were irrelevant. I asked why did I have to fill out 18 pages when his income was zero? They said, "We have no other forms so that's why we gave this to you." I just received a three-page form (for recertification) asking what's his income. It's still zero.

Minnesota requires both Utilization Review and Quality Assurance and Review. The federal government does not require those reviews. One agency estimated $13,000 annual savings by eliminating these two requirements. (The state would save a similar amount.) "Minnesota spends money foolishly."

Residential facilities spend two weeks doing paperwork for Quality Assurance and Review (QAR). No programming occurs during that interval.

One data sheet for one resident contains 1,633 data elements. We don't know if this form will satisfy the requirements of the Department of Human Services nor the Minnesota Department of Health. We use one sheet per resident and have direct care staff earning $5 per hour completing the forms. After three years of effort and 30 staff, we still don't have any baseline data for eight residents.

Licensing staff used to spend most of their time looking at individuals and providing feedback. Today, they look at paper and produce citations and timelines.

The current annual licensing system is paper-oriented and cursory while at the same time focusing on technicalities and trivialities. With the addition of many new licensed programs (primarily waivered service residences), the licensors are spread so thin that they typically run five months behind schedule. When they are available, their review is a checklist formality conducted in an adversarial manner.

Licensure is a total paper process. Our Vulnerable Adult policy is very long and legalistic. Every year, for the past six years, the DHS employee looks at the policy and says, "Reword how to turn off the main water valve. He hasn't read our rewrites but makes us change it annually." That citation doesn't change quality.

Half of our time is spent on paperwork, not people. No one sees the job I've done because licensing doesn't care. We aren't trusted by DHS.

Rule 53 is problematic. Reimbursement lags 22 months.

Rule 186 is a temporary fix. Payment is not timely.

OSHA has just released a letter that states all staff must receive hepatitis B vaccinations. The cost ranges from $100 to $300 per person. Even if we complied, we would not recoup our costs until 18 to 21 months later.

We can either help people or please government.

Medical assistance billing and prior authorization are of concern to many. The process is hurting people.

If a form is rejected or suspended, then there are problems with cash flow. Rejection occurs for minor problems, for instance, two letters touch each other. Phones are answered only three hours per week. It took over one year to get two billings paid for expenses from April 1991.

A caller expressed concern over the number of hours allotted per year by Medical Assistance for physical therapy. Physical therapy gets 30 hours per year, but occupational and speech therapy get 50 hours per year. "This is real inequity. People require more

than 30 hours. They need at least 50 hours. When additional hours are required through a prior authorization process, there are many problems... The waiting period to hear about approval or rejection is usually six to eight weeks... Rejections for prior authorizations are running about 70%. Only 30% are approved.

An occupational therapist called to say there has been a marked decrease in clients' abilities since Medical Assistance has put so many restrictions on occupational therapy services. Because prior authorizations will no longer allow sensory integration, there is a decrease in clients' ability. Speech therapists and job counselors are also noticing that clients are being further handicapped by this circumstance.

A number of suggestions were made to change the system.

I think it is very important that people who are making the laws should make it a point of going to the facilities and spend four to five hours working with the people. Then they would get a better idea of what is going on.

We applaud any efforts to streamline regulations. There are too many repetitive rules. Licensors have large caseloads. Licensing should occur biannually.

Licensing should occur once every two years rather than annually. Licensing doesn't do anything to help people.

We need a single licensing agency to reduce multiple quality assurance, SLF, ICF-MR, and DHS program rules.

Decrease paper compliance.

Clear planning is required to make sense of rules, regulations, and reimbursement. Conflicts exist between the federal and state governments. We must work out the conflicts in regulations.

We believe that the entire system would be well served by increasing licensing guidelines, and the timelines within the licensing rule itself, to at least two years. This would double the amount of time that the licensors have to conduct reviews, and we would also have more realistic time tables for review of policies and the implementation of changes. We would also like licensing to receive some customer relations training and to reverse their long standing policy of never providing positive feedback to programs. They told us they aren't allowed. Come up with alternative ways of measuring quality.

Why can't we have one form (referring to individual plans) that everyone uses?

Providers must have freedom within the regulatory system. We need to develop services; providers don't have the opportunity because we're chasing the rule. Either make it work or eliminate the rule. We need to go for standards.

Let's look at national accreditation rather than licensing. It's time to stop discussing it and get serious.

To avoid paperwork, we need to send people with disabilities to regular schools and regular jobs.

We've traipsed through two decades of regulation, now it's time to get to quality.

We need to treat people with dignity and respect.

Heavy-Handedness Is Not What Leadership Is All About

The Department of Human Services (DHS) doesn't know how to communicate.

DHS hasn't been able to figure out negotiated rates.

DHS gets an F on truthfulness.

I talked with federal officials who tell me that Minnesota is underspending the waiver, and Minnesota says everyone is getting served. The Minnesota waiver plan says families get a choice, but that's not what actually happens to families. Minnesota can apply for a targeted waiver but refuses to do so.

There's too much infighting. One division doesn't know the other. Everyone at the Department of Human Services has voice mail. No one returns calls. If they do, they don't have an answer or can't answer the question. It's a bureaucracy.

We need to have more cooperation between divisions. Currently, divisions act like they are independent countries.

I'm very concerned with the Department of Human Services administrative powers becoming untouchable.

The Developmental Disabilities Division is reactionary and oriented to cost-containment.

DHS should take care of the people and stop acting like God.

There is a Need for Team Work and Cooperation Within and Among Government Departments

DHS and Health must move from a regulatory model to training and technical assistance. Let's provide training through the technical college system.

We are all a team, but we don't act like one team. We need training, technical assistance, and advice.

Why are three different organizations asking the same employer to hire people with disabilities? DHS and the Department of Jobs and Training (DJT) should cooperate, but DHS licensing told us, "It's illegal to cooperate." Why the duplication?

The Department of Human Services and the Department of Health must work together.

P.L. 99-457, Part H, is being implemented in Minnesota. We need the full cooperation of education, health, and human services. If it's done well, families will benefit from coordinated services; be capable and well-informed.

Transition doesn't work in this state. DHS and Rehab don't talk to each other. In other states, the IEP supports the Transition Plan, not the reverse. No one knows numbers. No one begins efforts at age 14. In other states, there's a melding of services from schools to adult services. Here, it is start and stop.

When I worked in education, none of the teachers knew about case management and group homes; and they didn't care. We must have better coordination between schools and counties.

Education and Human Services must work together to reduce bureaucracy.

Two Systems

The state is running two systems: (a) its own with very high costs and salaries; and (b) community with low costs, but all the people. Funds should follow the person.

There's inequality between the state and community programs. There's no money for waivers, PCAs, and day training.

Half the funds go to ICFs-MR and RTCs. That is the biggest obscenity in the system.

Everyone is committed to community, but the funds are tied to the RTCs. It's easier to get funds if the person is institutionalized.

Both the Legislative Audit Commission and the Ombudsman documented all the problems of the system. Minnesota ranks in the top five of spending and the bottom five in money that reaches the people. While state rate increases equal 15 percent, community rate increases only 3 to 5 percent per year. The gap is growing wider. The taxpayer is robbed.

There is inequity in the system. DHS must look at how the funds are being spent. There is a misallocation of financial resources. In 1990, over $580 million were spent on services and 40% was spent on 5,618 people living in ICF-MR services or 8% of the people with developmental disabilities. This conclusion is not good fiscal nor social policy.

THEME FIVE:

Inequity of Resources– Inconsistency in the System

Participants in the town meetings were consistently preoccupied with the barriers to the creation of a community system of services and supports which will ensure lives of quality for people with developmental disabilities.

They noted many of the advances in Minnesota which have given a glimpse of what such a system and quality might look like.

They also identified great disparities in the system:

- There are really two systems, with quite different resources. The state operated system of facilities runs at high cost for relatively few people, while the community system runs at very low cost for a far greater number of people. "Inequity" between the two systems was a common theme.
- As a result, much of the money goes to maintaining a congregated, segregated system, and the administration of the system, rather than to people.
- There are tremendous differences across the state, and between rural and urban areas, in terms of what supports are available to individuals with disabilities and their families. Some saw these differences resulting from the various approaches of county governments.
- There is an apparent and marked bias in the system in favor of out-of-home placement, in contrast to supporting families to stay together.
- Each of these trends is inconsistent with the values and principles of community inclusion.

In simple terms, the problem was identified: **"The money does not match the need. The money rests with the type of service."**

And in equally simple terms, a response was commonly suggested: **"Money should follow people. Money should be controlled by the people."**

"The freezing of cost of living increases in the Day Training and Habilitation program rates is also of great concern. We are faced with increasingly difficult persons to serve, and also are being pushed in much more costly program directions. The program directions of community integration and supported employment are directions we have strived for and now have state support for but now the financial backing is pulled. We have, for many years, made do with the same money base; but with no cost of living increase, we cannot maintain let alone grow.

Some suggested ways out of this dilemma, and consequences if a way is not found:

Transfer funds from regional treatment centers to SILS, family support, personal care, respite care, crisis intervention, day training, employment, and waivered services.

Community programs are economical and provide quality.

Community programs are experiencing rising costs at all levels, but the per diems are frozen. Therefore, as a result, expect to see lay offs, larger ratios, clients falling through cracks, and fewer employment opportunities.

I resent it when we [community services] aren't paid enough. Minnesota wastes 20% of its money shuffling papers. SOCs cost $400, RTCs cost $280, and the community can't get $100 per day. The state is the problem. Begin with DHS and clean house. I resent them. They live off of us — I really am angry at the bureaucracy, but no one will help."

Geographical Differences — County to County, Rural vs Urban

There is incredible inconsistency between and among counties.

Where you live is the handicap rather than the person's disability.

We asked our county about the Title XIX waiver, and we were told it doesn't exist. It did exist, but we had to pursue it through Legal Advocacy.

DHS tells you about services that counties don't. DHS says, "Money is no problem," but good luck when you try to get it. Why do we have to call the state to get counties to do their jobs?

Our son is at home with nothing to do. We moved from [to a different part of the state], and we thought we moved into a different state or into a different country. We have the "best run around" system on the Range. There are more programs everywhere else in Minnesota.

It is more difficult for people with severe disabilities to live in rural areas. Health care professionals aren't serving people on Medical Assistance. Some individuals with disabilities have severe behavior problems which manifest themselves during office visits. Such behavior can limit access to community health programs.

Why does my daughter have to go to a program 70 miles away?

Why can't supported employment be set up throughout Minnesota?

"One person attended a Parents as Case Managers conference. A lawyer who spoke said that "my child has the right to a home; the right to stable, human relationships; and the right to be integrated. I'm so impressed." Yet, she lives 60 miles away. [My] County spends money for a new airport but no money for human services.

Individual needs can't be met in some communities when physical therapy isn't available.

Why do Murray County residents who need occupational therapy and physical therapy evaluation have to go to St. Paul? People are exhausted after this all-day trip. We need to move money and services to rural areas.

Why do young adults have to move from rural areas to the big city to get services? It's more cost-effective to stay in home communities.

Adult foster care is a viable alternative, but why is there no money? The foster care rate hasn't changed in five years in our county; but 25 miles away it is totally different. There's no consistency among counties.

We don't have affordable housing in rural areas that can be adapted and licensed under foster care. A lack of safe housing hinders our ability to move residents. If a client plans to move, then the rent goes up because it's "public money" and it's "those people." We don't have funds to repair dumps.

I want to move to Fairmont. My parents bought the house, but there are no SIL services so I can't move. I used to work on color tiles and ceramics, now I work at Mama Rosa's. I need all the money I can get."

Day programs have come off funding that was inadequate... This funding system was poor and had widespread disparity around the state and even between neighboring counties. The only pattern that seemed to appear was that rural programs that had difficulty attracting experienced staff and that had higher transportation burdens were receiving significantly less funding than programs in the metro area.

Now it has gotten worse. For the last two years, day programs have received less than the rate of inflation and for the next two years, we are scheduled to receive no increases in spite of the reality of inflation. With our costs rising ..., we have no choice but to freeze wages and reduce staff levels... Reduced staff levels will translate into worse client care and in all likelihood, institutional criminal neglect.

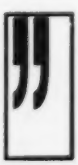
A Greater Commitment to Out-of-Home Placements than Families

The state makes it prohibitive for the family to stay together. Financially, we can't raise children on $200 per month. It is impossible. Families treat children with love, respect, kindness, and fairness. But the state spends all of its money on out-of-home placements.

The only way for a family to get help is to push the child out of the house. The state can prevent out-of-home placements at $30 a day rather than spending $215 a day for placement.

Our son is 25 years old and has Down Syndrome. There is no family support program to help him. We don't want an out-of-home placement.

Preference is given to regional treatment center residents. Families who kept their children do not receive help.



THEME SIX:

Community Programs and Support

Each of the town meetings expressed serious concern about the current status and future of community programs and supports. Many of the themes they identified are included in earlier parts of this report.

In general, and in terms of specific program areas, the comments were consistent.

"Community programs are experiencing rising costs, and their funding is frozen. The funding crisis is hitting all types of services in the community.

Funding has been frozen, but our costs continue to go up.

We want the best quality, but we fund at the lowest levels.

Regional treatment center residents continue to move to community programs, but the funds do not follow. These individuals have more complex needs.

The biggest difficulty is we can't get money for services or we can't fit the definition laid out by the bureaucracy. We must have more "go aheads" and "less red tape."

We are working at $62 per day, and have no funds to refurbish our place. The furniture is wearing out and the clients are wrecking it. It is really upsetting after visiting a $250,000 state operated community service home. I felt like crying... It is really disheartening to be required to provide the same quality services on a low per diem. It is hard to hire qualified staff at what we can afford to pay, and then train them... We are licensed for 15 beds, but have had only 10 clients for five years. We are penalized monetarily because we are not operating at capacity.

There is gridlock in the system. Waiting lists are long. People can not move out of inappropriate settings.

Minnesota needs to redirect funding for residential services. ICF-MR services are filled. Waiver diversions are impossible to get. "Young people graduate from high school and sit home." People are ready to leave the Regional Treatment Centers.

"There is a waiting list for the waiver.

It's been our choice to have our son live with us for 24 years. But now, we'd like a group home placement. The waiting list is ten years. It's discriminatory how parents who kept their children don't get services. Regional treatment center residents leave and go into town houses. My son will live in a dump.

In order for a person to move into the system, someone must die.

The process is a nightmare trying to understand diversions, conversions, and back filling.

No placements can occur in any residential facilities. Backfills are required. (A backfill means if a person is placed, the "slot" must be filled by someone from a Regional Treatment Center.)

Why is there so little for my homebound 30 year old son? He is on a list for a SIL program. We are entitled to this program. We are senior citizens who have had minimum help for 30 years. We don't live in town. We have to take him everywhere...

There are no group homes for married couples. There is a SILS available, but if candidates don't measure up to SILS requirements, they will not be accepted."

A host of community support strategies have proven to be cost-effective, viable, and helpful to people, yet they are not available throughout the state, or available in sufficient quantity anywhere in the state. Throughout this report, comments refer to:

- early childhood services,
- integrated public education,
- transition programs,
- supported employment,
- family support,
- a range of residential programs,
- a range of day programs, etc.

And, the most consistently mentioned program that is unavailable is respite.

The biggest concern for young families is the lack of respite care. There is no break. There's no time alone, no help to get away, and no support group.

The TEFRA program is wonderful for our daughter who is severely, multiply disabled. We have in-home LPN services, but there's no out-of-home respite. Because of our daughter's disability, we need a hospital setting because problems come up quickly.

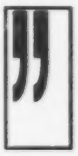
DHS approved but hasn't released the respite funds. The handling of grants and contracts is totally insane. Why does it take so long to get money that's due to us?

DHS released guidelines for respite care that were the opposite of input received in advisory meetings.

We don't have respite care. We need more cooperative babysitting services. We do need training.

There's no place to go when the family has an emergency. No funds for respite.

Respite needs to be provided on a proactive basis.



A number of people who called the toll free number commented on the lack of response by generic services.

I think that Legal Aid has too much of an impact on what happens when they represent one person and rarely take any additional clients... I know other advocacy groups have had to pick up people who have fallen into the cracks and have been denied services by Legal Aid.

A caller has had clients who have experienced sexual and physical abuse of clients in community group homes and other community facilities. When the caller phoned crisis lines, the crisis staff said they do not have training to deal with clients who are mentally ill or developmentally disabled. The caller has also contacted the American Cancer Society about a client's mastectomy. The Cancer Society said the same as the crisis center.

Some group homes will not allow abusive behavior to be reported to outside agencies. They consider it to be normal behavior, therefore, do not call a crisis center.

There is a clear need to plan for an aging population with developmental disabilities, but to also ensure that they are supported with respect and dignity, and in ways consistent with their individual needs. In each town meeting concerns around aging and retirement were expressed.

We need retirement standards—a person should choose between training to move forward vs. simply living. Some people have been trying to learn to brush their teeth for decades. One person rebelled and was able to leave the system to live in a high rise by himself. The man said, "I've never been happier. I can go to garage sales and chase women."

You cannot retire from being retarded. Under the guise of retirement, DHS wanted to have people stay home so they could save money. Good senior programming is a good idea, but sitting in the back room of a foster home or group home isn't. Age alone isn't a criterion for retirement. Retirement doesn't mean stopping services because people will require more care, not less care.

Our county is being told that, "People in their 60s who have lived in nursing homes for years need to move out in order to have programming after their day program." DHS talks about individualization but then directs all the traffic.

Why can't elderly peop!e with disabilities enter a nursing home if that's what they need? Is there a double standard when the general population can enter a nursing home?

We must have a retirement policy. Why do people still go to work when they're past retirement age?

Retirement is proper when it is individualized. We need to respect choices. Base retirement on choices, not funding.

There is a big group coming... People with Down Syndrome are most likely to have Alzheimer's. An area of great need is aging services (programming and treatment).

People with developmental disabilities who are deaf, and people with epilepsy, were often identified as groups whose needs are not being met.

People with developmental disabilities who are deaf should not be isolated in group homes. We need to have fire alarm lights, training, and professionals who are deaf. Should there be special group homes for people with developmental disabilities who are deaf?

There is no foster care for people who are deaf and have other disabilities. We need deaf families who can be providers.

There is a lack of communication skills within residential and day program. Staff aren't trained. No one knows sign language.

We need training for all staff in all programs to be sensitive to people who are deaf. We need to have deaf professionals who work in community programs.

Epilepsy is an invisible disability. Schools aren't responding nor providing appropriate services.

Health and life insurance are not available.

We need more programs for Native Americans, the rate of seizures is higher.

DRS believes epilepsy is not a severe enough disability for services. Counties will not provide case management if a person has epilepsy. What constitutes developmental disabilities is the learning environment.

It is very difficult to get special education services, testing isn't reliable because of the frequency, timing, and nature of seizures. Subtle seizures cause memory, learning, and retention problems.

"Don't ignore the problems until it is too late. The result is underemployment and unemployment."

Study Group Recommendations:

1. INDIVIDUAL AND FAMILY SUPPORT

In Minnesota, individuals with disabilities and families with sons and daughters with disabilities do not receive the support, assistance, and services necessary for a quality life. Individuals and families experience lack of information, waiting lists (real and imaginary), lack of services, and inappropriate services. Where you live in Minnesota has been described as a bigger handicap than the diagnosed disability.

Problem:

Children with developmental disabilities have a right to a safe, permanent, stable, and nurturing family in the community;

Families with a member who has a developmental disability often experience additional physical, emotional, and financial stress associated with their caregiving responsibilities;

Families must be supported on an ongoing basis to assist them in meeting these responsibilities.

Discussion:

These findings are based on many national and state reports on family support:

1. Families are the greatest natural resource available to their children and are the major providers of support, care, training, and meeting other needs of their children who require long-term care because of a developmental disability and are living at home.

2. Regardless of the severity of their disabilities, children need families and enduring relationships with caring people in a nurturing home environment. As with all children, children with developmental disabilities need families and family relationships in order to develop to their fullest potential.

3. It is in the best interest of the state to preserve, strengthen, and maintain the family unit.

4. It is more cost-effective to provide services to children and adults with developmental disabilities living with their families than to provide out-of-home placements. Failure to provide the necessary supports to families with children requiring long-term care results in admission of children with disabilities to institutions, nursing homes, or foster care settings.

5. Children and adults with developmental disabilities have personal needs and preferences to live, to learn and grow, and to have enduring relationships. People with developmental disabilities have abilities, competencies, and dreams; they should be supported and encouraged to pursue their personal desires.

6. In recognizing the vital need for family supports, Minnesota established a pilot family support services program in 1975. The program has expanded since then.

7. There remains a great number of families in Minnesota who are not yet receiving family support services, or who are presently receiving services but are underserved.

8. Family supports should be responsive to the needs of families, rather than fitting families into existing programs. Refinement of existing family supports and the design of new services should increase opportunities for families to exercise control over the services and supports they received by emphasizing consumer empowerment and choice.

9. Family support projects in Minnesota which empower families by encouraging them to arrange and pay for needed services, supports, and goods have been successful in meeting family needs in an individualized and cost-effective manner.

Recommendations:

1. Place the individual with a disability and the family first in all disability policy decisions.

2. Designate the individual with a disability and the family as the customers. Ask the customer, respond to the customer, and base decisions on the customer's specifications.

3. Reallocate resources toward individual and family support. (See other recommendations regarding the waiver.)

4. Create supports and services that are individually and family centered. The family should identify needed supports and how those supports will be provided. The support must be reliable, ongoing, readily available, and change as needed.

2. INCREASE FUNDING LEVELS FOR COMMUNITY PROGRAMS TO MAINTAIN QUALITY PROGRAMS

Problem:

Personnel issues including recruitment, selection, training, and retention of staff are linked with the level of funding in community programs.

Discussion:

A national study published in 1992 by Braddock and Mitchell produced several findings:

WAGES

• Direct care wages have consistently been reported to be considerably lower than many other occupations. There is evidence that many direct care workers are earning a wage below the national poverty level.

• Wages for direct care workers in public institutions are generally 40-60 percent higher than wages for direct care workers in private community facilities.

• Factors contributing to the low wage level for most direct care workers include the historical wage differential between men and women, a wage bias against caregiving occupations, and limited funding available to many private community organizations.

TURNOVER

• Direct care turnover has had a significant negative impact on residential facilities in terms of both cost and quality of care.

• Although wages were consistently identified as an important correlate of turnover, there is general agreement that other factors also have an influence: benefits, facility size, facility age, per diem, client disability, staffing ratio, unemployment, and urban location.

• In 1989, the Minnesota Department of Employee Relations conducted a study of day and residential facilities. The average wage for public workers ($10.36) was 63.1 percent higher than for private workers ($6.36). The average annual rate of turnover was 13.9 percent in public institutions and 47.4 percent in community facilities. Average pay, health benefits, ICF-MR certification, and facility location were found to be correlated with turnover rates.

In addition to these issues, several state studies have documented problems with training provided to direct care staff. There is no career ladder in Minnesota. Changes in competencies are not reflected in salary increases. Training does not address fundamentals of how to teach people with disabilities. Training often consists of workshops offered in metropolitan areas. There are no incentives for either providers or employees to participate in training.

Recommendations:

1. The recruitment, selection, training, and retention of direct care staff must be addressed at all levels. Funding must reduce the gap between state employees and community staff salaries.

2. Training must address and promote human dignity, self-determination, and independence of people with developmental disabilities. Training should promote state of the art, be delivered locally, in a cost-effective manner, and be linked with technical assistance, follow-up, incentives, and consequences.

3. RENEGOTIATE WAIVERS

Recommendations:

Assemble a team of knowledgeable persons within state government and outside consultants to analyze the structure of existing plans and waiver agreements with the federal government and to determine what changes may be required to accomplish future policy objectives. Initiate negotiations with HCFA and other federal agencies as soon as possible for the purpose of amending the state Medicaid plans and waiver agreements to allow the state to accomplish the following:

1. Integrate sources of program and service funding to be allocated to individual consumers and allow them to pay for whatever individualized services they might need rather than allocating funds to programs and trying to fit individuals into programs, as is now the case.

2. Enable SILS programs to be covered as "waivered services" thereby eliminating the financial disincentive for counties to place people with developmental disabilities into SILS program and/or the incentive to place people in more restrictive and expensive residential programs.

3. Enable Medicaid funds to be used for ancillary community support services (for example, temporary crisis intervention services) that would permit a greater number of persons with developmental disabilities to receive residential services in less restrictive community settings.

4. Make sufficient waivered service placements available for all persons with developmental disabilities for whom such placements are the most appropriate residential setting.

5. Permit pooling or aggregation of funds from different sources to provide service coordinators or case managers with more flexibility to tailor services to individualized needs.

6. Eliminate the incentive for counties to choose inappropriate services based on cost.

Problem:

Federal requirements and mandates continue to be an impediment to delivering effective, consumer-friendly and individualized services to persons with developmental disabilities in a cost-effective manner.

4. ARRAY OF SERVICES

Problem:

One of the major problems with the system for delivering services to persons with developmental disabilities is that the state has invested 40 percent of all the public money spent on that population in capital and operationally intensive ICF-MR beds, both public and private.

Discussion:

The recent independent assessment that was made of Minnesota's Medicaid Home and Community Based Services Waiver Program suggests that moving actual or potential ICF-MR residents (including RTC residents) into home and community-based residential programs can result in savings as high as 50 percent, with no diminution in the quality of care and services. But the assessment also points out that even with the changes brought about through that program, Minnesota still remains heavily reliant on more expensive ICF-MR residential settings in comparison with other states. Thus, it appears that many of the persons with developmental disabilities still residing in ICFs-MR could be served in less restrictive community settings if certain kinds of community support programs were more readily available. This situation needs to be addressed as soon as possible.

Recommendations:

The following steps are recommended:

1. Summarize current assessment information for the 5,000 persons with developmental disabilities in ICF-MR services (or a statistically significant sample of them) to determine how many people, with appropriate community support, could be relocated to waivered service, SILS or other less restrictive community-based programs.

2. Develop a specific, time-phased plan for transition of persons (identified in step 1) to less restrictive settings.

3. Make long-term projections for the continuing need for ICF-MR services.

4. DHS should assist providers in designing and offering alternative services to ICFs-MR.

5. COORDINATION

Discussion:

Currently, the service system for persons with developmental disabilities involves at least four levels of government (federal, state, county, and school district). Without even counting the criminal justice and corrections systems, programs, and services for that population fall within the realm of eight state departments or independent agencies, namely: the Department of Human Services (virtually all programs and components); the Department of Education (special education programs, vocational programs, etc.); the Department of Jobs and Training (SSI eligibility determinations, vocational rehabilitation programs); the Department of Transportation (special transportation); the Department of Administration (Governor's Planning Council on Developmental Disabilities and assistive technology programs); the Minnesota Council on Disability (broad mandate to provide advice to the state and assistance to consumers with any kind of disability); and the Ombudsman for Mental Health and Mental Retardation (advocacy, consumer assistance, and system oversight).

Every state agency involved with people with developmental disabilities tends to focus only on the programs and services which fall within its jurisdiction and may be oblivious of or reluctant to address problems and issues that involve other state agencies. For example, supported employment, transition from school to adult life, and training of direct care staff all have interagency implications and require coordination. Although, when an independent agency, the Minnesota Planning Agency may have had its flaws and limitations, it did serve the purpose of addressing some policies, issues, and problems with interagency implications. With its demise, the state seems to have lost much of its capacity for effective interagency coordination.

Problem:

One of the primary reasons why the system for delivering services to people with developmental disabilities is fragmented and difficult for both providers and consumers to comprehend and deal with is that there is currently no effective mechanism for the state of Minnesota to formulate unifying and comprehensive policies and to identify, track, and address issues that extend across agency lines at the state level.

Recommendations:

Restructure the Executive Branch so that:

1. The state is able to develop, implement, and enforce comprehensive and unified policies on matters relating to persons with developmental disabilities.

2 Systemic policy issues (such as supported employment, transition, or training) that involve multiple state agencies are promptly brought to the attention of the Governor's Office where they can be addressed in a unified and comprehensive fashion.

3. Interagency cooperation and coordination on policies and issues that cross agency lines can be monitored, facilitated, and, if necessary, enforced.

4. Disability issues are linked to the Health and Human Services Cabinet Cluster. For example, the Cabinet should be expanded to include the Department of Jobs and Training and the Department of Administration.

5. These recomendations are coordinated with the CORE Commission recommendations related to restructuring the Executive Branch.

6. Within DHS there is internal, centralized coordination of functions related to developmental disabilities in order to be user friendly.

6. INDIVIDUAL SERVICE COORDINATION (ALSO KNOWN AS CASE MANAGEMENT)

Problem:

Currently, the service system for persons with developmental disabilities involves at least 4 levels of government (federal, state, county, and school district), 8 state departments or independent agencies (without counting the criminal justice and corrections systems), 22 major program areas, and 32 different funding streams.

These programs and services are not well integrated or coordinated for the consumer or family members. Individuals and families are often left in a maze when attempting to obtain services which meet the needs of specific individuals.

Recommendations:

Provide individuals with developmental disabilities and their family members with a single, continuous point of contact with the services system (service coordinator) where all of these individual threads are woven together into a seamless plan that is continuously responsive to individual needs. To accomplish this, other actions, including the following, need to be taken:

1. Unify Services Coordination: Currently, individuals with developmental disabilities may have multiple service coordinators at the school district, county, and state levels for different purposes and kinds of services. Tying all of these multiple threads together into relatively simple packages for consumers is the responsibility of multiple government levels.

2. Reallocate More Resources into Service Coordination: Currently, the average county case worker is responsible for the service coordination of 50 to 60 people with developmental disabilities. In specifie instances, the ratio is even worse. We recommend an average ratio of no more than 30 to 1. If one were contemplating a more unified system where the case worker was responsible for pulling numerous threads together, the ratio might have to be even lower. Unification of service coordination responsibility from multiple agencies into a single agency might make resources available to bring the ratios down. For example, the recent independent assessment of Minnesota's Medicaid Home and Community Based Services Waiver Program suggests that using waivered services as an alternative to RTC and private ICF-MR placement yielded an estimated net savings of $29.3 million federal and state dollars from 1987 through 1991. Since effective service coordination is essential to being able to deliver lower-cost and more individualized residential services, some of the savings could and should be redirected into service coordination.

3. Create a Service Coordination System with Some Quality Assurance Controls: There is currently no effective system for assuring and controlling the quality of service coordination services provided to individuals.

   One way of approaching this problem is through a voucher system that would permit consumers to choose their own service coordinators. In our economic system, competition usually tends to drive quality up and costs down. But competition alone may not do the job.

   There needs to be some form of continuing and independent quality assurance review of service coordination. One approach is to empower an appropriate agency to conduct periodic quality assurance reviews of a statistically significant sample of service coordinator's work in each county.

Another approach is to develop a mechanism whereby consumers and consumer advocates can register concerns about service coordination and submit them to mediation or conciliation. Perhaps a combination of all these approaches can be employed.

Infuse elements of consumer choice into the service coordination system.

4. Give Service Coordinators the Flexibility to Access Services to Meet Individual Needs and Preferences: Virtually all of the various kinds of public services for people with developmental disabilities are circumscribed by very rigid eligibility, program, funding, and licensing rules, metaphorically a series of "round holes." The work of the service coordinator primarily involves finding the nearest fit, no matter how awkward it might be, and forcing the individual (the metaphorical "square peg") into it. Service coordinators who are seriously interested in meeting individual needs must now expend a great deal of time and energy finding ways to work around the system to make it meet individual needs. Correcting this situation will necessarily require a number of other reforms, such as more flexible program and service models, pooling funding streams, and separation of gatekeeping from other functions.

7. ALTERNATIVE APPROACHES TO QUALITY

Discussion:

At the present time, the Department of Human Services relies primarily on sets of fairly rigid program rules which prescribe what providers participating in the program must do and what documentation they must maintain. There are several problems with this approach. What a provider puts on paper may or may not have any relevance to what is actually being done for a consumer or how it is actually affecting the quality of his or her life. To determine those things, a licensing agency must actually observe consumers and compare observations with what is on paper. DHS Licensing Division has neither the time nor personnel to do that. In fact, it appears that quality assurance review now consists mainly of reviewing documentation submitted by providers; on-site visits of some services appear to be relatively rare, being triggered mainly by problems in documentation or complaints. In short, the current quality assurance system can identify whether providers appear to be complying with documentation requirements, but it provides little assurance that what is on paper is being done in practice and few insights into whether programming is actually improving the quality of consumers' lives.

Problem:

The current scheme for ensuring the quality of services delivered to people with developmental disabilities, which consists primarily of rigid and prescriptive licensing rules and which emphasizes process over results, is largely ineffective.

Recommendations:

Apart from certain necessary prescriptive requirements, such as fire protection, life safety measures, etc., the system for assuring the quality of services provided to people with developmental disabilities should be overhauled to emphasize outcomes or actual improvements in the quality of consumers' lives:

1. One approach is to contract with providers for measurable outcomes—i.e., performance standards.

2. Quality assurance also needs to encompass actual observations of and communication with consumers to determine what is actually happening in their lives. Perhaps some quality assurance funding would be better spent on caseload reduction and giving service coordinators a greater role in the quality assurance process. If service coordinators had relatively low caseloads and were able to spend more time in direct contact with consumers, one could contemplate frequent reviews to assess progress.

3. Immediately reduce regulations, duplication, and unnecessary paperwork.

4. Pilot test alternative methods of quality assurance.

5. Develop locally available training and technical assistance capacity. Offer incentives for individuals and providers to participate in training.

6. Licensing should take a more consultative role and look at frequency of licensing reviews based on the performance of the provider. No legislative action is needed to make this change.

8. QUALITY ASSURANCE FUNCTIONS

Problem:

The system the state has developed for ensuring the quality of the programs and services delivered to people with developmental disabilities (and other Minnesotans with special needs) is fragmented and full of duplication, redundancies, and, occasionally, complete gaps.

Discussion:

There are inherent problems and conflicts of interests associated with having quality assurance functions (i.e., licensing, survey, complaint investigation and enforcement, quality assurance review, etc.) housed in the same agency that develops, administers, and funds the programs and services whose quality is being assessed. First, there are conflicts caused by pride of ownership—that is, a single department can be expected to be reluctant to embarrass itself by emphasizing activities that are essentially designed to reveal shortcomings in program development, implementation, and administration. Second, related to pride of ownership is the tendency toward collegiality. In other words, it is difficult for one group of employees within a department to take actions that reflect adversely on other employees of the same department. Third, when funding and quality assurance are housed in the same department and come into conflict, as they naturally can be expected to do on occasion, resolution of those conflicts frequently involves significant policy choices. When those choices are made internally within an agency and not in a context that is "in plain view," policy is effectively being made—frequently without the knowledge of the commissioner or other senior agency staff.

Because of the current fragmentation of quality assurance functions relating to health and human services programs, redundancies and gaps in service occur. A prime example is the Vulnerable Adult Act, Minn. Stat. 626.557, under which local law enforcement, county social service agencies, and state licensing agencies concurrently share responsibility for investigating and taking action on instances of abuse or neglect of vulnerable adults. Because of the redundancy built into the Act and because an incident may bring multiple program and professional licensure agencies into play, it is not uncommon for half a dozen different agencies to conduct separate vulnerable adult investigations of a single incident and arrive at conflicting conclusions and results.

Because of continuing changes in the marketplace, many kinds of new and innovative programs relating to health care and human services require multiple licensure from multiple agencies. There are quality assurance considerations which all licensed programs share in common, such as fire protection, other life safety considerations, etc. It would seem that a more effective and less costly approach would be to unify all licensure programs, impose "core" requirements on all of them, and handle program differences through application of different licensure modules.

There is also the problem of proliferating health and human services professional licensing boards which have proven to have only limited efficacy in developing and enforcing standards of practice. At last count, there were at least ten independent state agencies performing those functions, each with separate staffs, overhead expenses and usually meager investigatory resources. Although all have de jure responsibilities to conduct vulnerable adult investigations involving the professions they license, none have ever really assumed that responsibility, thereby creating a de facto gap in the Act's coverage. Bringing them under a single umbrella with program quality assurance functions could produce a continuity in quality assurance activities that the state has never been able to achieve. Moreover, there would almost invariably be savings associated with pooled office overhead, staff, and investigatory resources, not to mention savings associated with conducting single, rather than multiple, investigations.

Finally, all of the quality assurance activities mentioned above are functionally similar, if not identical. The only differences relate to the subject matter of licensure. As things now stand, expertise in subject matter must be duplicated internally in agencies that have both program and licensing responsibilities. It is unlikely that much, if anything, would be lost by duplicating that expertise in two different state agencies. For example, in connection with current long-term care programs, the responsibility for program and funding resides in DHS while the responsibility for quality assurance resides in MDH, and that division of responsibility seems to work well and has the added benefit of containing some checks and balances which do not now exist in many in many programs and services for people with developmental disabilities.

Recommendation

Consolidate health and human services quality assurance functions.

9. PLANNING DATA

Problem:

We do not have complete and accurate data on the total number of people with developmental disabilities in the state, on the demographics of that population (i.e., age, sex, racial and ethnic factors, etc.), or on the nature of their relative needs.

Discussion:

Comparing incidence rates available from the Department of Health with the number of people with developmental disabilities currently being served by school and social service systems, it appears that there may be a significant number of people with developmental disabilities who are not currently receiving any support services. We do not know how many of these individuals may have disabilities so mild that they do not need services or how many are simply unserved or underserved. Additionally, the data bases currently being maintained on the population with developmental disabilities by various state agencies and units of local government are not all compatible, and information cannot be collated and shared easily. For example, we do not currently have accurate and precise information on the relative needs and dependencies of children with developmental disabilities in the school system; if we had better information of that kind, it would be much easier to project future demand for services within the social service system.

In connection with a recent study, the Department of Administration's Management Analysis Division spent thousands of hours manually collating, integrating, and interpreting data on total public expenditures for people with developmental disabilities for 1990. It would be extremely helpful to planners and policymakers if information such as that could be generated by computer rather than by manual analysis and be available annually.

Recommendations:

To engage in intelligent planning, the state needs a uniform and relatively accurate data base of information on the demographics and needs of people with developmental disabilities, as well as up-to-date data on how public funds are being used to serve that population. The following steps are recommended:

1. Determine exactly what information about the state's population of people with developmental disabilities is required for all state agencies to formulate relatively accurate and comprehensive service plans for the future.

2. Determine exactly what information is currently available from state agencies, counties, school districts, etc., and the various formats of that information.

3. Determine what information gaps currently exist that may impede the state's ability to plan for services on a statewide basis.

4. Redesign the data systems now being used by state agencies, counties, and school districts to collect better and more complete information on the demographics and needs of the state's population with developmental disabilities so that pertinent data can be collated and shared for planning purposes.

5. Require counties to maintain accurate waiting lists of persons with developmental disabilities who have applied for services but who have not yet been provided with those services. Waiting lists should indicate why services have not yet been provided.

6. The demographic and needs information currently available on the state's population with developmental disabilities should be supplemented with statistical surveys or sampling designed to provide the state with information about those persons with developmental disabilities who are not currently receiving services so that policy-makers and planners have a better indication of the potential future demand for services and the kinds of services that may be required.

7. Redesign the data systems now being used by state agencies, counties, and school districts to enable the tracking of all public expenditures across agency lines on an annual basis to determine with a reasonable degree of specificity where money is flowing and being spent.

8. Address any data practices issues that may arise as a result of integrating data bases. It would appear that in most cases, only data in the aggregate are needed for policy formulation and planning purposes so designing a system that only permits sharing data in the aggregate may be one approach to minimizing data practices issues.

10. GUARDIANSHIP

Problem:

Because of the potential and actual conflicts of interest that exist within the current system, appropriate public guardianship services are not always being provided to those persons with developmental disabilities who require them.

Discussion:

There are approximately 5,600 Minnesotans, all of whom have developmental disabilities, who are being represented by public guardians as "wards of the state." Currently, county social service workers are functioning as public guardians under the overall direction of a state guardianship office, which is part of the Department of Human Services.

Among the problems which public guardianship poses for the state, the most serious is the potential for conflicts of interest within the governmental agencies that provide and supervise guardianship services. Both DHS and counties have programmatic and funding responsibilities and therefore are responsible to the public for the cost of treatment, care, and services. On the other hand, a public guardian is not simply a representative of a consumer; in law, the guardian is the consumer. As long as guardians and program managers serve the same master and draw their paychecks from the agencies that plan and fund programs, there is an inherent conflict of interest and danger that service decisions will be dictated more by the cost of services than by what is in the individual consumer's best interests.

Recommendation:

Transfer the overall responsibility of the Department of Human Services to oversee public guardianship and the specific responsibilities of counties to act as public guardians to either a separate and independent state guardianship office or at least to another state agency where there is relatively little potential for conflict of interest.

We gratefully acknowledge the outstanding effort of Miriam Karlins in coordinating the town meetings and the toll-free, call-in day.

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The text was prepared by Audrey Clasemann, Bruce Johnson, Bruce Kappel, and Colleen Wieck.

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